Dignity in the care of older people with dementia in hospital

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Mental health problems are common in older people in hospitals

- > ½ of people in hospital over 70 have “cognitive impairment”
- 1/3 have depression
- ½ of people who fracture their hips have dementia
- Only 1/3 of people over 70 in hospital do NOT have a mental health problem
- Associated with severe dependency


Mental health problems and loss of dignity

- Stigma (shame) of loss of mental and physical prowess in a culture that values them
- Vulnerability:
  - self management
  - self advocacy
  - frailty (e.g. strength, immunity, nutrition)

Every system is perfectly designed to produce the results it gets

Better Mental Health study
care of older people with mental health problems in a general hospital

- 2008-2011
- Service Delivery and Organisation (SDO)
- Staff and organisational attitudes: interviews
- Patient and carer experience: interviews and observation

Arrival at the emergency department

“...and there’s all these signs up there, that they won’t tolerate aggressive behaviour, you know you will be asked to leave! And I’m thinking, oh my god, you know, they’re going to kick her out of here!”
Sally, daughter of Victoria

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Helpful advice

- "...we were told by the doctor that people with dementia don’t feel pain as much as somebody who hasn’t got dementia." Kirsty, granddaughter of Florence

Dignity

- He is agitated and frightened, crying with tears down his face. Not one member of staff offer any comfort or reassurance. The staff nurse tutts and reprimands him for losing more weight. The tears continue. Field notes, ward observation

- ‘Frank, let me help you get sorted out’, she takes his arm and leads him to the toilet. She comes out to get a clean pair of pyjamas, and goes back in. She is with him for about five minutes. I hear them talking to each other inside the bathroom. They emerge from the toilet and the staff nurse moves on to the next job. Frank says in a relieved tone ‘Thank you everyone’. Field notes, ward observation

Our explanation

- CORE PROBLEM
- Admission to a hospital is DISRUPTION TO ROUTINE
- For patients
- For carers
- For staff

- CORE PROCESS
- The response to disruption is to attempt to GAIN OR GIVE CONTROL
- Patients’ behaviours
- Carers’ actions
- Staffs’ actions

- The problem and process led to OUTCOMES
- Patient: fear, boredom, disorientation, exhaustion, stress, cycle of decline ... comfort, personhood, getting better
- Carer: embarrassment, indignity, frustration, anger, guilt, complaints ... reassurance, satisfaction, feeling supported

- "It is rare to see such a large proportion of any professional group feel so poorly prepared to take on the task in hand”

- "I just don’t think ... I’ve ever, ever, ever in my entire training, had any teaching about how to look after people with dementia.” Consultant

- "I don’t think we have enough...practical kind of element to the training. ... I don’t think I actually saw any old people...” Occupational Therapist

- "I would have loved to have been told, not told, but shown how to react and interact with these patients. I’ve been here for nearly two years and I’ve not been shown anything like that.” Healthcare Assistant

- "It should be mandatory that you have some form of training if you’re going to be given these patients, not just what the illness is about, but ways of actually being able to nurse properly.” Staff Nurse

- "They can’t do anything for themselves ... they won’t feed themselves, they can’t get out of bed themselves ... (you) can’t be sure they’re drinking, they’re often incontinent. The more of that patient group you have, the less care the others are going to get. They are hugely sapping of our scarce resources.” Consultant

- "Sometimes you’re more veterinary in your approach. And then you perhaps may not be treating them in the same way as someone else that you can talk to...” Consultant

- "It’s distressing ... you feel that you’re not really doing anything other than trying to calm them down, trying to cover them up ... then they start the whole thing all over again.” Staff Nurse

- “It’s knowing their likes and dislikes and what their routines are and what they’re capable of doing for themselves so you can, from day one, hopefully get them into that routine again. If they’ve got a particular night time routine... if they’re used to going to bed at seven o’clock, then we’d set them down for seven.” Deputy Ward Manager
Summary of findings

• Dignity for older people with dementia (and their carers) is under threat in hospitals
• The system is not designed for those who use it
• Mainly, staff are not trained, do not understand, and do not know what to do

Recommendations

• Culture shift: it’s core business
• Training of all staff at every level
• Routine involvement with carers
• Make environment suitable
• Liaison psychiatry?
• Recognise resource implication

Afterword: the TEAM study

• 300 patients usual care
• 300 patients “Medical and Mental Health Unit”
• Clinical effectiveness
• Cost effectiveness
• Experience & quality of care

Development of a specialist medical and mental health unit for older people in an acute general hospital


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